



**California Health & Human Services Agency
Center for Data Insights and Innovation
Data Exchange Framework Stakeholder Advisory Group
Meeting Summary
Thursday, June 23, 2022, 10:00 a.m. to 1:00 p.m.**

Attendance

Stakeholder Advisory Group Members in attendance: Jamie Almanza, Ashrith Amarnath, Charles Bacchi, Mark Beckley, Scott Christman, David Cowling, Carmela Coyle, Rahul Dhawan, Joe Diaz, Michelle Doty Cabrera, David Ford, Michelle Gibbons, Lori Hack, Matt Lege, Brent Houser, Cameron Kaiser, Andrew Kiefer, Linnea Koopmans, Cheryl Larson, Ali Modaressi, Erica Murray, Nathan Nau, Mark Savage, Linette Scott, Cathy Senderling-McDonald, Jim Switzgable, Juliana Vignalats, Claudia Williams, Leslie Witten-Rood, William York

Stakeholder Advisory Group Staff and Presenters in attendance: Dr. Rim Cothren (Independent HIE Consultant to CDII), Jonah Frohlich (Manatt Health Strategies), Dr. Mark Ghaly (CalHHS), Courtney Hansen (CalHHS/CDII) Kevin McAvey (Manatt Health Strategies), Marko Mijic (CalHHS), John Ohanian (CalHHS/CDII), Helen Pfister (Manatt Health Strategies), Elaine Scordakis (CalHHS/CDII), Nicole Shields (CalHHS/CDII), Jocelyn Torrez (CalHHS/CDII)

Public in attendance: approximately 77 public attendees joined this meeting via Zoom video conference or through call-in functionality.

Meeting Notes

Meeting notes elevate points made by presenters, Stakeholder Advisory Group Members, and public commenters during the Data Exchange Framework Stakeholder Advisory Group meeting. Notes may be revised to reflect public comment received in advance of the next Stakeholder Advisory Group meeting. Meeting materials, full video recording, transcription, and public comments may be found on the [Data Exchange Framework website](#).

Welcome and Roll Call

John Ohanian, Chief Data Officer, California Health & Human Services, welcomed attendees the ninth Stakeholder Advisory Group meeting. John reviewed the meeting agenda and introduced Stakeholder Advisory Group Members via roll call.

Vision and Meeting Objectives

Dr. Mark Ghaly, Secretary, CalHHS, thanked Stakeholder Advisory Group Members and public attendees for their engagement in the Data Exchange Framework development process. He reviewed the vision for data exchange in California and shared his reflections on the development of the Data Exchange Framework. Dr. Ghaly expressed his optimism that the Data Exchange Framework will produce meaningful

benefits for all Californians. He asked the Stakeholder Advisory Group Members to continue to engage in active listening and to keep individual Californians in mind as the Data Exchange Framework, Data Sharing Agreement, and Policies and Procedures are finalized.

Dr. Ghaly provided an overview of the next steps for Data Exchange Framework implementation. He also reviewed the status of proposals in the budget that would support implementation of, and signatory participation in, the Data Exchange Framework.

Jonah Frohlich, Senior Managing Director, Manatt Health Strategies, reviewed the meeting objectives, statutory timeline for the data exchange framework, and the total numbers of commenters and comments submitted for the Data Exchange Framework, Data Sharing Agreement, Policies and Procedures, and Strategy for Digital Identities.

Data Sharing Agreement Policies and Procedures

Helen Pfister, Partner, Manatt Health Strategies, summarized the comments received and modifications made to the sections of the Data Sharing Agreement for which there were substantive updates, which included:

- (3) Definitions
- (4) Use of Health & Social Services Information
- (5) Policies & Procedures and Specifications
- (7) Requirement to Exchange Health & Social Services Information
- (8) Privacy and Security
- (10) Individual Access Services
- (13) Legal Requirements

Stakeholder Advisory Group Members feedback on the updates to the Data Sharing Agreement included:

- **Section 4: Use of Health & Social Services Information**
 - Differing perspectives on the scope of the prohibition on exchanging information under the Data Exchange Framework with the intention to sell such data. Some suggested restricting the sale of data to circumstances where doing so would be beneficial to the individual; others supported aligning with the Health Insurance Portability and Accountability Act's (HIPAA) prohibition on the sale of confidential identified data rather than also including deidentified data.
 - Dr. Ghaly noted that the intent of this provision of the DSA is not to curtail appropriate and necessary data exchange [e.g., exchange of data to complete Supplemental Security Income (SSI) applications].
- **Section 5: Policies & Procedures and Specifications**
 - Suggestion to consider implementing standard processes and timelines for updating the Data Sharing Agreement and Policies and Procedures,

similar to how the Center for Medicare and Medicaid Services releases Medicare payment rules annually.

- **Section 6: Authorizations**
 - Request for confirmation that the current wording addresses circumstances under which HIPAA requires patient authorization to disclose certain kinds of data.
- **Section 7: Requirement to Exchange Health & Social Services Information**
 - Some Members requested clarification of the definition and timeframe(s) of “real-time” data exchange since some entities may face challenges engaging in real-time exchange. Other members supported the requirement to engage in real-time exchange.
- **Section 13: Legal Requirements**
 - Support for revisions regarding the individual choice to opt-out of sharing data, as is allowed for under existing California law.
 - Request for clarification on which individuals or entities would be prohibited from sharing information once an individual opts out of having their health and human service data shared.
 - Request for confirmation that HIPAA Business Associate Agreements do not trump the Data Sharing Agreement.
 - Suggestion that AB 133 does not provide authority to implement a Governance Entity [e.g., Health and Human Services (HHS) Data Exchange Board] and doing so would require new legislation.
- **General**
 - Recommendation to clarify which types of data exchanges the Data Sharing Agreement apply to (i.e., what types of data and between which entities) and which types of organizations are required to or encouraged to sign the Data Sharing Agreement. Doing so may help forestall confusion relating to data that is being exchanged outside of the Data Sharing Agreement.
 - Recommendation to be clear in communication to participants and providers about Data Sharing Agreement implementation requirements, including when the Data Sharing Agreement will be available for signatures.

Helen summarized the comments received and modifications made to each of the Policies and Procedures that will be released in July 2022 for which there were substantive updates, which included:

- (1) Amendment of Data Sharing Agreement
- (3) Breach Notification
- (4) Permitted, Required, and Prohibited Purposes
- (5) Requirement to Exchange Health & Social Services Information
- (6) Privacy and Security Safeguards
- (7) Individual Access Services

- (8) Data Elements to Be Exchanged (Reviewed by Dr. Rim Cothren, Independent HIE Consultant to CDII)

Stakeholder Advisory Group Members feedback on the updates to Policies and Procedures included:

- **(1) Amendment of Data Sharing Agreement**
 - Support for the change to extend the effective date of Data Sharing Agreement amendments from 45 to 180 days and recommendation to establish a standard cadence for amending the Data Sharing Agreement.
 - Recommendation to consider not requiring signatures from Data Sharing Agreement signatories for amendments to the Data Sharing Agreement.
- **(3) Breach Notification**
 - Request for clarification about whether the definition of breach is the same as HIPAA for covered entities, and suggestion to align with existing state and federal breach notification requirements, as appropriate.
 - Support for changes toward alignment with California's Statewide Health Information Policy Manual and request to reconsider the notification of the Governance Entity about a breach, which could be duplicative of the existing HIPAA requirements for breach notification.
- **(4) Permitted, Required, and Prohibited Purposes**
 - Request for clarification on whether the definition of "healthcare operations" policy aligns with HIPAA, since differing definitions could lead to administrative burden for Data Sharing Agreement signatories and present a barrier to data exchange.
 - Support for the establishment of technical assistance programs that will help entities understand what is required and what additional infrastructure is needed to meet Data Sharing Agreement requirements.
 - Concern that this Policy may inadvertently prevent the exchange of information critical to public health activities, such as the enforcement of public health orders and ordinances that are provided for under California law, through the exclusion of data exchange for the purposes of civil, legislative, or criminal investigations.
- **(5) Requirement to Exchange Health and Social Services Information**
 - Request for clarification regarding whether there is a requirement to proactively share data, as opposed to only responding to requests.
 - Suggestion for CalHHS to engage in stakeholder communication efforts to raise awareness about the Data Sharing Agreement.
 - Request for the state to consider legislation that would extend the statutory deadline of January 2023 for small practices to sign the Data Exchange Agreement.
- **(6) Privacy and Security Safeguards**
 - Request for clarification on how the Data Sharing Agreement and Policies and Procedures interact with the CalAIM data sharing authorization in CA Welfare and Institution Code Section 14184.102.

- **(7) Individual Access Services**
 - Support for requiring providers to develop processes by which individual users can request updates to their health and human service records.
 - Request for confirmation that the requirements in this Policy align with federal requirements with regard to individual's access to their health and human services data.
 - Request to consider starting by focusing on unidirectional access (i.e., view only) for individual users to their records before focusing on bidirectional access (i.e., view and propose changes) to their records.
- **General**
 - Request for clarification on whether stakeholders will have an opportunity to review documents before publication.

Jonah Frohlich reviewed policies and procedures next steps, including six P&Ps in development, including:

- Qualified HIO Designation Process
- Real-time Data Exchange
- Monitoring and Auditing
- Enforcement
- Information Blocking
- Technical Requirements for Exchange

Stakeholder Advisory Group Members feedback on the next steps for Policies and Procedures included:

- Request for clarification on whether forthcoming Policies and Procedures will start to be developed in July.

Public Comment

John Ohanian opened the meeting to public comment. No members of the public provided comments.

Data Exchange Framework Component Documents

Jonah Frohlich provided an overview of the comments received and updates made to Data Exchange Framework Documents, which included:

1. Data Exchange Framework Development Process
2. Data Exchange Framework Guiding Principles
3. California Data Exchange Landscape
4. Data Exchange Scenarios
5. Data Exchange Framework Governance

6. California Data Exchange Gaps and Opportunities

Stakeholder Advisory Group Members' feedback on the updates to the Data Exchange Framework Documents included:

- **(3) California Data Exchange Landscape**
 - Request for appropriate state agencies to review additional state data sharing initiatives.
- **(6) California Data Exchange Gaps and Opportunities**
 - Request for the state to consider ongoing funding to support Health Information Exchange Organization (HIO) infrastructure and local health departments.

Digital Identity Strategy Update

Dr. Rim Cothren summarized the comments received and updates made to the Strategy for Digital Identities.

Stakeholder Advisory Group Members' feedback on the updates made to the Strategy for Digital Identities included:

- Request to add more specific information to define gender identity.
- Comment that individuals experiencing homelessness may have their address listed as "general delivery."

Data Exchange Framework Implementation

Secretary Ghaly provided an overview of the process for Data Exchange Framework implementation strategy. He highlighted that transparency, clarity, and broad stakeholder engagement are key components to the strategy.

John Ohanian reviewed the timeline for Data Exchange Framework implementation. He noted that the Data Exchange Framework will launch on July 1, 2022. John highlighted that the current Stakeholder Advisory Group and Data Sharing Agreement subcommittee will sunset, and CalHHS/CDII will establish interim advisory committees to support implementation after July 1, 2022 before permanent governance, including a HHS Data Exchange Board, is established in 2023. He reviewed the charges, composition, and operations of the advisory committee and the HHS Data Exchange Board and provided an overview of the division of Data Exchange Framework governance functions between the Board and CDII.

Stakeholder Advisory Group Members feedback on Data Exchange Framework Implementation included:

- Support for the data exchange implementation process, governance approach, and requiring Board members to have expertise in HIE and administration of public and private health care and/or social service delivery systems.

- Request for confirmation on whether interim governance would continue after Q1 2023 if legislation to establish the HHS Data Exchange Board is not yet enacted. CDII responded that it would.
- Requests for clarification about process for establishing the interim advisory committees and expressing interest to be considered for these committees.
- Request for clarification about who will make up the new Stakeholder Advisory Group.

Closing Remarks

John Ohanian reviewed project next steps and noted that the final versions of the DxP, DSA, and initial set of P&Ps will be released in July 2022.

Appendix 1. Data Exchange Framework Stakeholder Advisory Group Member - Meeting Attendance (June 23, 2022)

Last Name	First Name	Title	Organization	Designee For	Present
Ghaly	Mark	Secretary (Chair)	California Health and Human Services Agency	N/A	Yes
Almanza	Jamie	CEO	Bay Area Community Services	N/A	Yes
Amarnath	Ashrith	Medical Director	California Health Benefit Exchange	N/A	Yes
Bacchi	Charles	President and CEO	California Association of Health Plans	N/A	Yes
Beckley	Mark	Chief Deputy Director	Department of Aging	N/A	Yes
Bindman	Andrew	Executive Vice President; Chief Medical Officer	Kaiser Foundation Health Plan, Inc. and Hospitals	Adams	No
Cabrera	Michelle Doty	Executive Director	County Behavioral Health Directors Association of California	N/A	Yes
Christman	Scott	Chief Deputy Director	Department of Health Care Access and Information	N/A	Yes
Cowling	David	Chief, Center for Information	California Public Employees' Retirement System	N/A	Yes
Coyle	Carmela	President and CEO	California Hospital Association	N/A	Yes
Dhawan	Rahul	Associate Medical Director	MedPoint Management (representing America's Physician Groups)	Crane	Yes
Diaz	Joe	Senior Policy Director and Regional Director	California Association of Health Facilities	Cornett	Yes
Fisher	Kayte	Attorney	Department of Insurance	N/A	No
Ford	David	Vice President, Health Information Technology	California Medical Association	Corcoran	Yes
Gibboney	Liz	CEO	Partnership HealthPlan of California	N/A	No
Gibbons	Michelle	Executive Director	County Health Executives Association of California	Chawla	No

Last Name	First Name	Title	Organization	Designee For	Present
Hack	Lori	Interim Executive Director	California Association of Health Information Exchanges	N/A	Yes
Hernández	Sandra	President and CEO	California Health Care Foundation	N/A	No
Houser	Brent	Chief Deputy Director, Operations	Department of State Hospitals	N/A	Yes
Kaiser	Cameron	Deputy Public Health Officer	County of San Diego (representing the California Conference of Local Health Officers)	Relucio	Yes
Kiefer	Andrew	Vice President, State Government Affairs	Blue Shield of California	Markovich	Yes
Koopmans	Linnea	CEO	Local Health Plans of California	N/A	Yes
Larson	Cheryl	Director & CIO	Department of Corrections and Rehabilitation	Toche	No
Legé	Matt	Government Relations Advocate	SEIU California	N/A	No
Lindeman	David	Director, CITRIS Health	UC Center for Information Technology Research in the Interest of Society	N/A	No
Lo	Julie	Executive Officer	Business, Consumer Services & Housing Agency	N/A	No
McAllister-Wallner	Amanda	Deputy Director	Health Access California	Wright	No
McCallin	DeeAnne	Director of Health Information Technology	California Primary Care Association	Beaudry	No
Modaressi	Ali	CEO	Los Angeles Network for Enhanced Services	N/A	Yes
Moore	Dana E.	Acting Deputy Director	Department of Public Health	N/A	No
Murray	Erica	President and CEO	California Association of Public Hospitals and Health Systems	N/A	Yes

Last Name	First Name	Title	Organization	Designee For	Present
Nau	Nathan	Deputy Director, Office of Plan Monitoring	Department of Managed Health Care	N/A	Yes
O'Malley	Janice	Legislative Advocate	California Labor Federation	Pulaski	No
Savage	Mark	Managing Director, Digital Health Strategy and Policy	Savage & Savage LLC	N/A	Yes
Savage-Sangwan	Kiran	Executive Director	California Pan-Ethnic Health Network	N/A	No
Scott	Linette	Chief Data Officer	Department of Health Care Services	N/A	Yes
Senderling-McDonald	Cathy	Executive Director	County Welfare Directors Association	N/A	Yes
Switzgable	Jim	Deputy Director	Department of Developmental Services	Bargmann	Yes
Vignalats	Julianna	Assistant Deputy Director	Department of Social Services	N/A	Yes
Williams	Claudia	CEO	Manifest MedEx	N/A	Yes
Witten-Rood	Leslie	Chief, Office of Health Information Exchange	Emergency Medical Services Authority	N/A	Yes
York	William	President and CEO	211 San Diego/Community Information Exchange	N/A	Yes